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# Cancer Control Planning and Establishment of Priorities for Intervention by a State Health Department

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## Synopsis .....

*A number of data sources routinely available to State health departments were analyzed as part of a*

*State health department cancer control planning effort. This planning effort consisted of seven steps; the most challenging one was the establishment of priorities for cancer control interventions. Using data from available sources, however, a framework for prioritizing potential cancer control interventions as well as choosing a geographic area in which to implement selected interventions was developed. Factors considered in this framework for setting intervention priorities included the magnitude of the problem; the existence of scientific consensus regarding the efficacy of intervention techniques; the availability of data needed to plan, implement, and evaluate an intervention; the availability of resources within communities to implement an intervention; and the existence of public demand for the intervention.*

*The development and use of this cancer control planning model and framework for setting cancer control intervention priorities in New York State are described in this paper. In using this planning model and framework for setting priorities, quantitative elements were found to be most necessary to define problems, but qualitative elements were most crucial for decision making.*

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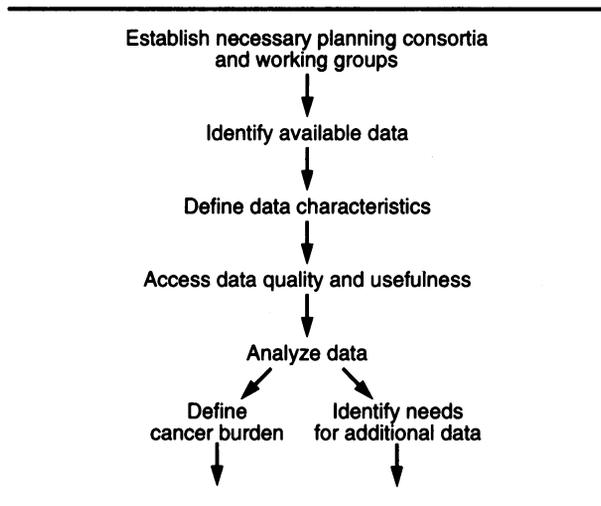
**I**N 1986, THE NATIONAL CANCER INSTITUTE (NCI) issued a report that set forth an ambitious goal, a 50 percent reduction in the 1980 age-adjusted cancer mortality rate by the year 2000. To achieve this goal, specific cancer control objectives and recommendations were established for reduction in tobacco use, early detection of breast and cervical cancer, diet modification, access to state-of-the-art treatment, and reduction of environmental or occupational exposures (1). It was recognized that State health departments needed to play a key role in achievement of these objectives through greater involvement in cancer prevention and control. To facilitate this involvement, the NCI initiated the Data-based Intervention Research (DBIR) Program, a program of grants and cooperative agreements awarded to State health

departments to build ongoing cancer control programs that would ensure the translation of cancer prevention and treatment science into practice. The New York State Department of Health was one of the first six States funded under this Program in 1987.

All DBIR grantees were to conduct four phases of activity: data identification and analysis, cancer control planning, intervention implementation, and evaluation. Each grantee was free to devise an approach that met the unique needs of its State. An important public health research product from the DBIR Program was the description of demonstrated strategies for cancer control planning.

Boss and Suarez (2) have previously described the types of data sources identified and analyzed during phase I by each first round grantee, including New

## Cancer control planning model



York State. This paper will expand upon their work by providing an account of the cancer control planning process used by New York to use data to define the State's cancer burden and to set priorities for cancer control intervention. This planning process included identification of a specific intervention and the geographic location for its implementation. The figure is a flow chart for conceptualizing the steps involved in data-based cancer control planning.

The specific strategies used in New York for accomplishing each step will be described in detail subsequently. Further, a framework for establishing cancer control intervention priorities, the most difficult step in the planning process, is advanced. This planning process and framework for setting intervention priorities can provide an important foundation for other public health agencies in their cancer control efforts.

### Using Planning Consortia, Working Groups

The initial step in New York State's planning process was the establishment of a consortium of approximately 12 persons to address the tasks involved in the identification and review of data. Consortium members consisted of staff from the New York State Department of Health, Roswell Park Cancer Institute, and Memorial Sloan-Kettering Cancer Center. These persons represented a variety of disciplines including clinical oncology, cancer control, epidemiology, health promotion and education, and behavioral sciences. The consortium met monthly for 12 months. Its efforts were devoted primarily to the identification of data and review of State health department staff analyses.

In addition, the DBIR project staff sought input from the New York State Department of Health Data Management Group. This committee included members with backgrounds in epidemiology, health promotion and education, and biostatistics. Over the course of the grant, this committee provided internal technical review of preliminary products and rapid feedback to DBIR staff. Project feedback also was provided by technical staff at the NCI who assisted on an as-needed basis as well as through review of grant progress reports.

Involvement of these groups enabled the project to make use of a wide range of technical expertise not available within the Bureau of Cancer Epidemiology and to develop additional support for subsequent cancer control activities. Even broader community involvement was achieved through a Cancer Control Advisory Panel established by the New York State Commissioner of Health. This panel gave final approval for the prioritization and selection of the cancer control intervention suggested by project staff.

### Identifying Data

Project staff began identifying data sources potentially useful for cancer control planning. At the time, sources of data such as death certificates, cancer incidence registries, and hospital discharge records had not been widely used for cancer control program planning and evaluation.

A total of 27 different sources of data were identified for evaluation. Some of these data sources were ongoing surveillance systems, such as disease and exposure registries. In general, these were population-based and collected information on all New York State residents. Other sources included smaller surveys that were frequently limited to a specific subpopulation, such as clients of family planning services or Hispanic residents of New York City. In addition to these data sources, CAN\*TROL (3), a PC-based software program that models cancer incidence and mortality rates based on potential intervention effects, was identified as a resource. A more detailed account of identified data sources, including those identified by other DBIR grantees, was provided by Boss and Suarez (2).

### Defining Data Characteristics

Once available data had been collected, project staff could begin to identify the characteristics of each data source, particularly those that would influence the usefulness of each source. Of special concern was the overall quality of the data; data of

low quality were not considered useful. Identified characteristics included geographic coverage, years for which data had been collected, relevance to specific cancer control issues, level of detail available, an organized approach to quality assurance, reporting completeness, and accuracy of individual data items. These latter three characteristics collectively enabled the staff to make an overall assessment of data quality.

For those nonpopulation-based data sources that collected information on subgroups of New York State residents, assessment of reporting completeness was replaced by three more relevant characteristics, adequacy of sampling design, sample size, and response rate. For these surveys, the quality assessments focused on the adequacy of procedures used to select the sample and the methods to collect the data.

### **Assessing Data Usefulness and Quality**

**Population-based data sources.** The box on page 794 shows the characteristics of each population-based data source. In general, these data systems collect information about health status on all New York State residents on a continuous basis. Nearly all of these sources had been in existence long enough for trend information to be available. Although all data sources were relevant to cancer control, some were not detailed enough to be useful for planning. For example, only 5 percent of the records of the Heavy Metals Registry pertained to chemicals that could cause cancer and therefore would not allow analysis of worker exposure, critical to cancer control planning efforts. The decision to drop certain data sources from the study was made by project staff based on evaluation of data quality and the relevance to cancer control.

All population-based data sources reported having mechanisms in place to assure the quality of the data being collected. Some assurance of data quality is needed so that interventions developed to address an identified need are not misdirected. The New York State Cancer Registry, for example, routinely analyzes the percent of reports originating from mention of cancer on the death certificate but without a corresponding report from a hospital or laboratory. The proportion of reports with diagnoses of cancer which are not fully specified or with critical data elements missing is also routinely examined. The existence of such quality control measures provided reassurance that the majority of the data were accurate. For a number of data bases, completeness of data was also influenced by the existence of a legal mandate requiring data to be reported. In general,

population-based data sources were used most extensively in the planning process, since they afforded the best opportunity for assessing trends.

**Nonpopulation-based surveys.** The second box, on page 797, presents a summary of characteristics of surveys that collected information on subgroups of New York State residents, primarily as special studies. Many other surveys were identified and evaluated, such as the smokeless tobacco use survey and the teenage health survey. These are not shown in the box, because many of these surveys were from studies designed to address a limited issue and lacked a broad enough application to facilitate cancer control planning. The age of the data for some surveys was a critical factor in determining use. Other surveys covered very limited geographic areas, such as a survey of teenagers' use of smokeless tobacco that was conducted in three adjacent rural counties. In addition, because data from such surveys only represented one or two points in time, they were not useful for determining possible trends.

The majority of ongoing surveys listed in the box on page 794 collected data from all geographic areas of the State. Many collected information across a number of years, enabling some trend analysis. The existence of techniques for ensuring data quality were examined. For example, sampling frames were assessed to evaluate whether the samples were representative of the population as a whole. In general, information about nonrespondents was generally lacking, and most relied on self-reported information.

### **Analyzing Data**

Next, the data were analyzed to gain a clear picture of the State's burden of cancer as well as to identify some contributing factors, including individual risk factors or low levels of screening. Practical, state-of-the-science approaches to risk reduction or early detection could be identified from the literature to address the specific problems identified. The results of these analyses were critical to all subsequent planning steps. Mortality and incidence rates, percent distribution of different types of cancer, probabilities of developing specified cancers, annual health care costs, number of cancer-related hospital discharges and patient days, years of potential life lost, lost productivity costs, cancer screening patterns, risk factor patterns, and availability of health care services were examined. Such analyses were generated for various cancer sites, population subgroups, and geographic regions.

## Sources and Characteristics of Population-based Data for New York State

Data sources and area and years covered	Are data elements relevant to specific cancer control issues?	Is level of detail available for individual data elements?	Reporting complete?	Individual data items accurate?
<b>New York State Department of Health:</b>				
Cancer registry, exclusive of New York City, since 1950, statewide since 1973	Yes	Yes	Yes, reporting legally mandated	Yes
Statewide Planning and Research Cooperative Data System, statewide since 1979	Yes	Yes	Yes, reporting legally mandated	Yes
Family planning data system, statewide since 1973	Yes, within population served by clinics	Yes	Yes, funded clinics under contract to report	Yes
State Pap smear proficiency testing program, statewide since 1974	Yes	Since unit of analysis is Pap smear, not patient, screening rates cannot be derived from data	Yes, reporting legally mandated	Yes
Heavy metals registry, statewide since 1981	Only 5 percent of reports pertain to chemicals known to cause cancer	Yes	Yes, reporting legally mandated	Yes
Mammography quality assurance program, statewide since 1987	Yes, main program focus is on quality of mammogram	Screening not distinguished from diagnostic mammograms. Since unit of analysis is mammogram, not client, rates cannot be derived	Yes, mandated inspection of units occurs every 1-2 years	Yes, in addition to inspection data, facilities estimate the number mammograms
Vital records mortality data, statewide since 1958 (computer readable form)	Yes	Yes	Yes, reporting legally mandated	Yes
Vital records occupation and industry, data State, exclusive of New York City since 1980	Yes	Yes	Yes	Yes
<b>New York State Department of Taxation and Finance:</b>				
Cigarette tax information, statewide since 1977	Yes	Since unit of analysis is tax on packs sold, smoking prevalence rates cannot be derived	Yes, except for sales outside New York State	Yes

## Sources and Characteristics of Population-based Data for New York State (Continued)

Data sources and area and years covered	Are data elements relevant to specific cancer control issues?	Is level of detail available for individual data elements?	Reporting complete?	Individual data items accurate?
New York State Department of Environmental Conservation: Industrial chemical survey, statewide since 1976	Yes	If chemical use is a trade secret, it is reported but is not available through the data base. Since unit of analysis is pounds used, proper use cannot be determined	Yes, reporting is legally mandated for all companies with State pollutant discharge permits	Yes
Roswell Park Cancer Institute (RPCI):				
Roswell Park tumor registry, RPCI patients since 1971	Yes	Yes	Yes	Yes
Roswell Park patient epidemiology data system, RPCI patients since 1957	Yes	Yes	Yes	Yes
U.S. Department of Commerce: U.S. census data, national, each decade since 1970	Yes, for developing rates based on population	Yes	High	Self-reported data

NOTE: All sources take an organized approach to insuring the quality of the data.

In addition, Smoking Attributable Morbidity, Mortality, and Economic Costs (SAMMEC) software was used to calculate a number of smoking-related statistics, including direct and indirect health care costs for smoking. CAN\*TROL software was used with State-specific information on incidence and mortality to model changes expected from a given intervention effort. These projections provided critical insight into the potential impact of a cancer control measure, insights that were not always apparent from simple descriptive analyses of the data.

### Defining the Cancer Burden

The results of these analyses, viewed together, define the State's cancer burden within the context of available data. A summary document prepared by project staff entitled "Cancer in New York State" was reviewed by the Data Management Group and then distributed throughout the State (4). This document brought together available data in a way

that clearly characterized the cancer problems in New York State. The document is a product of an interactive process of data analysis, review, followup analysis, and rereview. It provided the foundation to set priorities and identify and select an intervention, and it served as a catalyst for garnering support for cancer control in the State.

### Prioritizing the Cancer Burden

Having defined the overall cancer burden in terms of data, staff used these data and other information, such as knowledge of community resources, to establish priorities for cancer control interventions. Priorities needed to be established both for the area of cancer control that would be addressed and the location where the intervention would be implemented. Following a brief review of the framework used for establishing these priorities, the specific application in the New York project will be described.

*'The age of the data for some surveys was a factor critical in determining use. Other surveys covered very limited geographic areas, such as a survey of teenagers' use of smokeless tobacco that was conducted in three adjacent rural counties.'*

**Establishing intervention priorities.** A framework for considering the most relevant factors for setting priorities for cancer control intervention was established. This framework involved assessing data relevant to each of the six NCI cancer control priority areas in terms of five factors, including (a) magnitude of the problem; (b) scientific consensus about the efficacy of intervention models or techniques; (c) availability of data to plan, execute, and evaluate an intervention; (d) availability of networks or liaisons and resources within the community; and (e) public demand or political pressure for the intervention.

This approach provided a systematic mechanism for considering the competing factors used in setting priorities. In addition, it highlights the diversity of factors to be considered in program planning. The first three factors (magnitude of the problem; scientific consensus regarding the efficacy of intervention techniques; and availability of data needed to plan, execute, and evaluate an intervention) were quantitative. These quantitative factors were essential in prioritizing potential cancer interventions. The second two factors (availability of networks or liaisons and resources within the community and the existence of public demand or political pressure for intervention) while qualitative, were also important in selecting interventions once need was demonstrated by the quantitative factors.

*Magnitude of the problem.* Assessment of the magnitude of the problem was based on five additional factors:

- Impact of the cancer on the population as a whole. Data most useful for assessing overall impact of the cancer on the population were incidence, mortality, and years of potential life lost. These data were obtained from the New York State Cancer Registry and from vital records.
- The impact of the cancer on specific subpopulations. For some cancers, such as occupation-related cancers, the impact on subpopulations can be extensive, but the impact on the total population may be

small. Information about the cancer's impact on subpopulations could be used for targeting interventions. With effective intervention targeting, a significant reduction in these cancers could then be achieved. Thus, the extent to which different types of cancers were differentially affecting selected segments of the population was examined using available data for various sociodemographic groups. Computer mapping was used to identify geographic areas with excess disease burdens.

- Impact of the cancer on the medical care system. Using the State's hospital discharge data, the number of hospital discharges and days of hospital care associated with each type of malignancy were tabulated.
- Time trends in incidence. Trends in incidence were examined using data from the New York State Cancer Registry. These analyses enabled identification of those cancers with a moderate current or low incidence, but potentially may pose a large problem in the future. Mortality trends were evaluated using information from vital records.
- Risk factor prevalence. Risk factor prevalence in New York State was obtained through New York State's Behavioral Risk Factor Surveillance Surveys. Cancer control data at the time of this evaluation were limited; since this DBIR project has begun, however, questions have been added on mammography use, sun exposure, and dietary practices.

The goal of this approach was to determine where the greatest impact could be achieved with limited intervention resources. Determining the magnitude of the burden would enable us to direct resources where they are most needed. This determination, however, is tempered by the fact that scientifically proven intervention strategies or approaches are not available for some cancers that have a large impact on health.

*Scientific consensus regarding the efficacy of intervention models or techniques.* Because proven intervention strategies for cancer control are limited, the project narrowed its scope to those six areas identified by NCI as having the highest national priority for cancer control. Within these six areas, the efficacy of some interventions are supported by the science more than others. More is known about interventions to reduce tobacco use compared with those to modify diet, for example. Screening mammography has been shown to be effective in reducing mortality for women ages 50 and older (5). In addition, reductions in mortality among women younger than age 50 became apparent after more extended followup periods (6). Further, many inter-

## Characteristics Used to Assess the Data Quality and Usefulness of Nonpopulation-based Surveys

Data sources and area and years covered	Are data elements relevant to specific cancer control issues?	Is level of detail available for individual data elements?	Is sample size for overall target population and important sub-populations sufficient?	Response rates	Individual data items accurate?
New York State Department of Health: Behavioral Risk Factor Surveillance System, statewide, 1983, 1985 to present	Some elements, such as tobacco, diet, mammography, skin cancer prevention	Yes, for socio-demographic variables, limited number of survey questions	Yes, for total, limited for some subpopulations	58 percent	Self-reported data
Cancer control and health risk behavior surveys, State (exclusive of New York City) 1980-86	Yes	Yes	Yes, for total, limited for some subpopulations	68-78 percent	Self-reported data
Roswell Park Cancer Institute and American College of Surgeons Commission on Cancer: Patterns of care data base, national, yearly since 1976	Yes	Yes	Yes	High	Yes

NOTE: All sources take an organized approach to insuring the quality of data. Sampling frame and sampling design are adequate for all sources.

vention approaches have been tested and proven effective in increasing screening mammography (7). Because only limited resources were available, funds needed to be directed to those interventions proven to have an impact.

*Availability of data needed to plan, execute, and evaluate an intervention.* While data are critical to defining the burden of cancer and establishing priorities for intervention, they serve an equally critical role in carrying out an intervention. Data are needed for understanding target audiences and tailoring intervention approaches, for implementing systems to provide feedback about intervention progress, and for evaluating whether the intervention has had any effect on the problem. Population-based data sources or special surveys may not be the most appropriate sources of data for these purposes in that they cannot provide necessary and timely feedback about program implementation. Availability of data needed to evaluate effectiveness of an intervention is especially critical. Such data are often collected as

part of a specific evaluation plan; however, data from ongoing surveillance efforts may be critical to assessing overall public health impact. For example, stage of disease at diagnosis can be monitored over time using cancer registry information.

*Availability of networks or liaisons and resources within the community.* The availability of community resources, including networks or liaisons, affects the ability to intervene once a problem has been defined, proven techniques for intervention are identified, and sufficient information has been gathered to plan and execute an intervention. Some intervention approaches are more labor intensive or expensive to implement effectively than others, and resources are often limited. Thus, the potential availability of community volunteers or State or local funding to supplement existing project resources has important intervention implications. The existence of service or advocacy networks in the community also underscores that a given priority identified in the planning process is a concern shared by the community. This

### OCCUPATIONAL CANCERS

#### *Magnitude of the Problem*

- Impact on the total population:<sup>1</sup> Data not available for State estimates. Doll and Peto<sup>2</sup> discuss the problems of estimating cancer risk attributable to occupation nationally, but provide a “guesstimate” of around 4 percent of all cancer deaths are occupational.
- Impact on subpopulations:<sup>1</sup> Data not available.
- Impact on medical care system:<sup>3</sup> Data not available.
- Current trends in incidence<sup>4</sup> and mortality:<sup>1</sup> Data not available.
- Patterns of risk factor or screening prevalence: Data available only on the number of workers in hazardous occupations.

*Scientific consensus regarding the efficacy of intervention models or techniques:* A number of relationships between occupational exposures and cancers have been established.

*Availability of data needed to plan, execute, and evaluate interventions:* Difficult to target specific groups of workers based on data.

*Availability of networks or liaisons and resources within the community:*<sup>5</sup> State-sponsored occupational health clinics provide services to workers with possible occupational diseases. Right to Know Program to alert workers about potentially hazardous substances.

*Public demand or political pressure for intervention:* Demand among some occupational groups.

### SUN EXPOSURE

#### *Magnitude of the Problem*

- Impact on the total population:<sup>1</sup> Incidence—8.7 per 100,000 males, 6.4 per 100,000 females. Mortality—3.0 per 100,000 males, 1.5 per 100,000 females. Years of potential life lost—3,466. Number of cases 1,301. Percent of total cancers—2 percent for males, 1.6 percent for females. Five-year survival—83 percent. Stage I, 96 percent, stage II, 77 percent, stage III, 46 percent, stage IV, 20 percent.
- Impact on subpopulations:<sup>1</sup> Higher rates among persons in higher socioeconomic groups.
- Impact on medical care system:<sup>3</sup> 1,661 discharges, 15,278 hospital days.
- Current trends in incidence<sup>4</sup> and mortality:<sup>1</sup> Incidence—21-percent increase for males, 14-percent increase for females. Trends in incidence since 1950—fivefold for males, threefold for females.
- Patterns of risk factor or screening prevalence: Prevalence of sun exposure and behaviors such as sun-screen use unknown.

*Scientific consensus regarding the efficacy of intervention models or techniques:* Effective strategies for reducing sun exposure have not been developed and the efficacy of screening modalities not established.

*Availability of data needed to plan, execute, and evaluate the intervention:* State-specific data on risk factors and behaviors not available. Small area incidence, mortality, stage at disease, and resource availability data for targeting high-risk populations.

*Availability of networks or liaisons and resources within the community:*<sup>5</sup> No information available on prevention programs in local areas.

*Public demand or political pressure for intervention:* Public generally unaware of growth of malignant melanoma as a public health problem.

### DIET-RELATED CANCERS

#### *Magnitude of the Problem*

- Impact of on the total population:<sup>1</sup> Data not available for State estimates. Doll and Peto discuss problems of estimating cancer risk attributable to diet nationally, but provide a “guesstimate” of around 35 percent of all cancer deaths are related to diet.
- Impact on subpopulations:<sup>1</sup> Data not available.
- Impact on medical care system:<sup>3</sup> Data not available.
- Current trends in incidence<sup>4</sup> and mortality:<sup>1</sup> Data not available.
- Patterns of risk factor or screening prevalence: State or local data on dietary patterns not available; national dietary information available.

*Scientific consensus regarding the efficacy of intervention models or techniques:* The role of fat and fiber in cancer development is not fully understood.

*Availability of data needed to plan, execute, and evaluate intervention:* State-specific data only available for prevalence of being overweight.

*Availability of networks or liaisons and resources within the community:*<sup>5</sup> No information available on prevention programs in local areas.

*Public demand or political pressure for intervention:* Diet generally seen as individual choice, public perception of link between diet and cancer unclear.

### SMOKING-RELATED CANCERS

#### *Magnitude of the Problem*

- Impact on the total population:<sup>1</sup> Lung cancer incidence—87.7 per 100,000 males, 37.8 per 100,000 females. Lung cancer mortality—73.9 per 100,000 males, 29.2 per 100,000 females. Years of potential life lost—30,155. Number of cases—11,506. Percent of total cancers—20 percent for males, 11 percent for females. Five-year survival—13 percent. Stage I, 41 percent, stage II, 10 percent, stage III, 5 percent.
- Impact on subpopulations:<sup>1</sup> High lung cancer rate among black males. Five-year survival among blacks—10 percent.

## Establishing Cancer Control Priorities in Six Areas

- Impact on medical care system:<sup>3</sup> 18,712 discharges, 296,754 hospital days.

- Current trends in incidence<sup>4</sup> and mortality:<sup>1</sup> Incidence rates have remained level for males over time period, 41 percent increase for females.

- Patterns of risk factor or screening prevalence: Decrease in smoking between 1983 and 1987:<sup>6</sup> 33 to 25 percent for males, 28 to 22 percent for females.

*Scientific consensus regarding the intervention models or techniques:* Well-defined techniques for smoking prevention and cessation available.

*Availability of data needed to plan, execute, and evaluate intervention:* Only statewide smoking data available. Rates for sociodemographic groups are based on small numbers and therefore are unstable. Census data available. Data on current disease may not reflect current smoking patterns.

*Availability of networks or liaisons and resources within the community:*<sup>5</sup> Smoking prevention and cessation activities sponsored regularly in local areas.

*Public demand or political pressure for intervention:* Demand for Clean Indoor Air Act.

### CERVICAL CANCER

#### *Magnitude of the Problem*

- Impact on the total population:<sup>1</sup> Incidence—17.5 per 100,000 for in situ, 8.0 per 100,000 for invasive. Mortality—2.7 per 100,000. Years of potential life lost—3,310. Number of cases—2,069 for in situ, 1,030. Percent of total cancer—8 percent. Five-year survival—66 percent. Stage I, 85 percent, stage II, 58 percent, stage III, 36 percent, stage IV, 15 percent.

- Impact on subpopulations:<sup>1</sup> Greater impact on black and Hispanic women and women in lower socioeconomic groups; higher in urban and rural areas, lower in suburban areas.

- Impact on medical care system:<sup>3</sup> In situ—2,681 discharges, 13,045 hospital days. Invasive—2,616 discharges, 31,121 hospital days.

- Current trends in incidence<sup>4</sup> and mortality:<sup>1</sup> Incidence—35 percent decrease for in situ, 21 percent decrease for invasive. Trend since 1950—65-percent decline in incidence of invasive cancer, 79-percent decline in mortality.

- Patterns of risk factor or screening prevalence: Pap test every 2 years<sup>6</sup>—90 percent among ages 18-39, 73 percent among ages 40 or older. Pap test annually<sup>7</sup>—60 percent, triennially<sup>7</sup>—82 percent. Older, less educated women less likely to be screened.

*Scientific consensus regarding efficacy of intervention models or techniques:* Pap test effective screening technique; women remaining unscreened may be generally medically underserved.

*Availability of data needed to plan, execute, and evaluate intervention:* Small area incidence, mortality, stage of

disease, and resource availability data for targeting high-risk populations.

*Availability of networks or liaisons and resources within the community:*<sup>5</sup> Planned Parenthood screening. State sponsored programs to provide outreach to minority women. Existence of statewide quality assurance program.

*Public demand or political pressure for intervention:* Women at highest risk with lowest screening rates are least likely to demand services.

### BREAST CANCER

#### *Magnitude of the Problem*

- Impact on the total population:<sup>1</sup> Incidence—96.1 per 100,000. Mortality—32.5 per 100,000. Years of potential life lost—19,318. Number of cases—10,754. Percent of total cancers—28 percent for females. Five-year survival—74 percent. Localized, 90 percent, regional, 68 percent, distant, 18 percent.

- Impact on subpopulations:<sup>1</sup> High mortality and lower survival among black women.

- Impact on medical care system:<sup>1</sup> 14,304 discharges, 163,034 hospital days.

- Current trends in incidence<sup>4</sup> and mortality:<sup>1</sup> 9-percent increase in incidence. Trend since 1950—75-percent increase with stable mortality.

- Patterns of risk factor or screening prevalence: Breast screening for women ages 50 to 70.<sup>8</sup> Mammograms—15 percent, physical examination—45 percent. Attributable risk for known risk factors not sufficient for directed screening.

*Scientific consensus regarding the efficacy of intervention models or techniques:* Mammography shown to be effective in women ages 50 and older. Less consensus exists concerning women ages 40 to 49.

*Availability of data needed to plan, execute, and evaluate intervention:* Small area incidence, mortality, stage of disease, and resource availability data for targeting high-risk populations.

*Availability of networks or liaison and resources within the community:*<sup>5</sup> Determined levels of mammography equipment generally adequate to meet demand in local communities. One million dollars in funds allocated for local screening programs by State legislature. Existence of statewide quality assurance program.

*Public demand or political pressure for intervention:* High public and political demand for addressing problem.

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<sup>1</sup>1985 data on incidence, years of potential life lost, and number of cases from New York State Cancer Registry for New York State (exclusive of New York City). Mortality data from New York State Vital Records. Survival data

(Continued)

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## Application of the New York State Framework for Establishing Cancer Control Priorities in Six Areas (Continued)

from 1985 Annual Cancer Statistics Review, National Cancer Institute.

<sup>2</sup>Reference 9.

<sup>3</sup>Average annual number of hospital discharges and days, 1980–86, Statewide Planning and Research Cooperative System.

<sup>4</sup>“Time Trends in Cancer Incidence, 1977–1986,” New York State Cancer Registry.

<sup>5</sup>Based on municipal health plans submitted by county departments of health.

<sup>6</sup>Data from Behavioral Risk Factor Surveillance Surveys, 1983 and 1987.

<sup>7</sup>Reference 12.

<sup>8</sup>“Public Awareness and Use of Cancer Detection Tests: 1983 Survey,” American Cancer Society.

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community interest can contribute to intervention success and continuity beyond the project period.

*Existence of public demand or political pressure for intervention.* Consideration of public demand may seem at odds with a systematic, data-based approach to establishing priorities for action. However, public health does not exist in isolation from politics (8). Public demand can reflect the magnitude of a problem in the context of community values. Some elements of a cancer issue that conventional quantitative indicators might miss are its importance relative to other health issues, to quality of life, or the psychological impact of diagnosis or treatment. In this project, public concern was assessed by the volume of inquiries to the Cancer Registry and the Cancer Surveillance Program, reflecting concern both from the public at large and from elected officials.

**Selecting a cancer control area for intervention.** The third box, on page 798, illustrates the use of the framework to establish priorities among the potential cancer control areas for intervention in New York State. Setting priorities was particularly important, given the limited funds available through the grant to conduct and evaluate interventions.

*Occupational exposures.* While there was scientific consensus that a number of industrial chemicals are known carcinogens, it was difficult to assess the magnitude of the cancer problems associated with occupational exposure, primarily because of a lack of available data. Further, data that were available were not detailed enough to identify and target groups of workers at increased risk. Thus, although risk might be high for some workers, it was difficult to estimate the potential impact of occupational interventions. Based on this lack of State-specific data and the fact that known industrial carcinogens account only for around 4 percent of all cancer mortality, the magnitude of impact was considered low.

*Sun exposure.* Ultraviolet radiation from the sun is associated with the development of malignant melanomas and other forms of skin cancer (10). Incidence and mortality rates due to malignant melanoma in New York were low relative to other cancer sites under study. However, there were substantial increases in the number of new cases over time; mortality data indicated poor survival among those diagnosed in later stages. Guidelines obtained from the Physicians Data Query (PDQ) (11) indicate that by avoiding excess sun exposure, especially among high-risk persons, such as those with a family history of skin cancer, many skin cancers can be prevented.

Studies of public knowledge, attitudes, and behaviors regarding sun exposure and cancer are an important precursor to developing effective primary prevention interventions. Few studies of this type could be found. Also, screening in the general population has not yet been shown to be effective in reducing mortality. Therefore, no proven interventions could be planned as part of this project.

Given incidence trends, however, a population-based survey was undertaken as part of New York State's ongoing efforts to address the need for behavioral data at the State level. Questions also were added to New York State's Behavioral Risk Factor Surveillance Survey in 1989 and 1993.

*Diet modification.* The magnitude of the cancer problem attributable to diet proved to be difficult to assess. Not enough was known of the role of fat, fiber, and other nutrients at the time of our evaluation to predict reductions in cancer incidence resulting from dietary change. There is a growing body of literature regarding what changes in diet need to be made and how to accomplish them; methods for long-term dietary changes still remain to be tested. State-specific information needed to plan, implement, and evaluate interventions were not available. For example, it was not possible to identify groups at highest

disease risk or monitor dietary changes. Also, we had little information about diet-related cancer prevention programs in the community. A statewide survey of dietary practices has since been conducted.

*Reduction in tobacco use.* Tobacco-related cancers were found to have a major impact on health. Thirty-three percent of all deaths of males and 19 percent of all deaths of females in New York were attributable to smoking in 1985. Although incidence rates among men appeared to be leveling off, rates among women continued to rise. Smoking prevalence had declined among both men and women.

The scientific evidence supporting the efficacy of prevention and control efforts was overwhelming, and well defined techniques were available. However, information available to target an intervention to high-risk areas or groups required a level of data on smoking prevalence not yet available. The sample size of the Behavioral Risk Factor Surveillance System provided calculations of smoking prevalence only on a statewide level. However, a statewide smoking control effort was not possible because of limited resources under this grant. Public demand for reductions in tobacco use had focussed on environmental controls, such as New York State's passage of a Clean Indoor Air Act, which had the potential for a broad impact. In addition, it was anticipated that funding would be available in the future to address more adequately tobacco use in New York.

*Cervical cancer early detection.* Cervical cancer accounts for around 1,000 invasive cases and 500 deaths each year in New York State. Mortality attributed to cervical cancer has declined significantly in New York. Currently cervical cancer is responsible for around 3,300 years of potential life lost in New York State, contrasted with more than 30,000 lost due to lung cancer, and more than 19,000 attributed to breast cancer (4).

Strategies for reducing mortality from cervical cancer are limited to early detection through Papanicolaou (Pap) testing since the means for its primary prevention is not known at this time. Howe and Bzduch (12) found that 60 percent of New York State women utilized Pap screening annually; 82 percent were screened every 3 years. Community resources for increasing Pap screening were being provided by maternal and child health programs.

Women remaining unscreened for cervical cancer also were medically underserved for general preventive health care. To increase Pap screening in this group would have required that barriers to regular preventive medical care be addressed and, although

important, were beyond the scope of the project.

*Breast cancer early detection.* Approximately one-fourth of newly diagnosed cancers among women in New York State were breast tumors (around 10,000 each year). Approximately 3,700 deaths are attributed to breast cancer each year. In addition, there has been a steady increase in incidence of breast cancer incidence over time.

Reducing mortality due to breast cancer is limited to early detection. The efficacy of mammography in decreasing mortality has been demonstrated (5,6). Further, a variety of intervention strategies involving public education and provision of services have been found to be effective (7). Only about 15 percent of women nationally reported regular mammographic screening (1).

Since 1987, the New York State Legislature had allocated funding to the New York State Department of Health to support community-based breast cancer detection and education programs. Through outreach activities, comprehensive breast cancer services are targeted to underserved women. In addition to legislative action, public concern about breast cancer was evident from inquiries to the New York State Cancer Registry.

Breast cancer thus represented a reasonable intervention target due to the magnitude of the public health impact; the proven efficacy of the available screening approaches; the intense public, legislative, and professional interest in this form of cancer; and the availability of community-based resources.

**Choosing a geographic area for intervention.** Based on the framework criteria developed, we decided to make breast cancer a focus for intervention as part of the DBIR grant. Other priorities not addressed by limited DBIR funds were undertaken through other State initiatives. The next step involved selection of a geographic area with a high-risk population suitable for the DBIR breast cancer intervention. The same framework for selecting a cancer control priority area was used. Information compiled from the analyses of data bases specific to breast cancer was again used as a basis for this decision.

*Magnitude of the problem.* Historical data were examined on a county-by-county basis to select an area of the State appropriate for a breast cancer intervention. Nassau County was identified as an area that has had high breast cancer mortality rates for the past four decades. It has consistently ranked as one of the top four counties in the State for breast cancer incidence. Further, the county is one of the most

*'Nassau County was identified as an area that has had high breast cancer mortality rates for the past four decades. It has consistently ranked as one of the top four counties in the State for breast cancer incidence.'*

populous in the State with a population of 1,300,000 residents. More than 900 breast cancer cases are diagnosed in Nassau County each year.

*Scientific consensus regarding the efficacy of intervention models or techniques.* Effectiveness of screening would not be expected to vary by geographic area. New York State has a mammography quality assurance program in place statewide.

*Availability of data needed to plan, execute and evaluate an intervention.* Data were available concerning women's breast cancer screening practices in Nassau County on which to base an intervention (13). These data showed that a large percentage of women visited a physician at least once in the previous year, and around a third of women practiced breast self-examination monthly. Only 10 percent of women studied, however, reported receiving a screening mammogram annually. Only 8 percent of the women diagnosed with breast cancer had their cancers detected because of a mammogram. Since women generally had access to a health care provider, mortality attributed to breast cancer could be improved if greater numbers of women could be encouraged to receive mammograms regularly. An intervention could be targeted to women or to their physicians. A successful intervention would increase both screening and seeking information about screening services.

*Availability of networks or liaisons and resources within the community.* Among the regions in New York State with networks and community resources, the Nassau County Department of Health had already made a significant commitment to addressing breast cancer. The department purchased several state-of-the-art mammography units and had committed to provide breast cancer screening and education services to all women regardless of their ability to pay. In addition, the New York State Department of Health had provided funding to Nassau County Department

of Health to conduct outreach programs for underserved women. It was decided to complement this strong local effort by utilizing funds from the DBIR grant to develop an intervention to increase public and professional awareness. This intervention was conducted, and evaluation is underway.

This approach allowed us to maximize the impact of breast cancer interventions by coordinating grant-based activities with existing State and local programs. We felt this integration of programs was an effective means of maximizing grant resources. Coordination with an existing program also meant that we could build upon existing liaisons between the State and the local community. In this way, effort that would otherwise be directed to coalition building and goal setting could be turned directly to planning, conducting, and evaluating the intervention.

*Existence of public demand or political pressure for intervention.* Concern about breast cancer was high in Nassau County. Although studies of breast cancer in the area had been conducted (unpublished data of New York State Department of Health, "Summary of Findings, Long Island Breast Cancer Study: June 1988-April 1992"), there was public and political demand for more to be done. Breast cancer received extensive coverage in the media in the area. In addition, a number of public meetings were held to enable local groups and health professions to voice their concerns.

## **Conclusion**

The experience in New York State suggests that State and local health departments have access to data that are useful in cancer control planning and the establishment of priorities for public health action. Combined with a systematic approach to planning, these data provide a solid foundation for ensuring that limited resources are directed to areas of greatest need and support efforts with the highest probabilities of success.

The planning process used by New York State presented in this paper enables the limitations of available data to be identified and considered in describing the cancer problem and making decisions about public health interventions. Characteristics of the data can be the basis for assigning greater weight to some data than to others. The specific framework used for establishing priorities for cancer control intervention depends on these data. However, public health efforts do not exist apart from personal and community values, public demand, and political trends. Decision making needs to be flexible and

responsive to fluctuations in resources, changing public health needs, new scientific advances, and State and local priorities.

The application of this planning process and framework for setting intervention priorities in New York State also revealed several other important facts. First, data were unavailable for a number of cancer control areas that may otherwise have been chosen for intervention. Work on this project enhanced recognition of the lack of information in some priority areas and stimulated developments to collect it. This effect was particularly notable for data relevant to skin cancer prevention.

Second, the data that were available were most useful to assess the impact of various forms of cancer on the population and to identify subpopulations with unusually high rates of disease or exposures to known risk factors. These data provide the foundation for targeting intervention efforts.

Third, assessment of information specific to local communities and target groups was important for several reasons. Trends in the local community may differ from those noted nationally or statewide. For example, in New York State, lung cancer had not surpassed breast cancer in mortality rates as it has nationally. These data can also provide the foundation for evaluating intervention outcomes: funding sources are not likely to continue funding in the absence of demonstrated effectiveness. Public and elected officials expect information about their individual communities to be available, they expect health officials to be knowledgeable about national efforts and the state-of-the-science, and they expect decisions about public health actions to be defensible. Work on this project also stimulated efforts to continue to provide small-area cancer data to local officials and planners.

Finally, it is hoped that the planning process and framework for setting priorities used by New York might be useful in conducting similar efforts in other States. Components may need to be modified as available data increases and cancer control planning expertise grows. Our experience, however, strongly supported the use of a systematic approach to planning and public health action.

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